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Who Will Care for Me Next? Transitioning to Adulthood With Hydrocephalus

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KEY WORDS

hydrocephalus, health transition, medical education, advocacy

ABBREVIATIONS

PCMC—Primary Children's Medical Center

IH—Intermountain Healthcare

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abstract

OBJECTIVES: Hydrocephalus is a prototypical chronic condition that follows children into adulthood. The objectives of this study were to (1) review how the health care needs of young adults with hydrocephalus are not being met, (2) estimate the numbers of adults with childhood-onset hydrocephalus, (3) describe a novel program to provide care for young adults with hydrocephalus and other chronic pediatric conditions, and (4) propose national strategies to promote successful hydrocephalus transition care.

RESULTS: Adults with hydrocephalus need continuous access to expert surgical and medical providers. Existing care models fail to meet this need. The number of young adults who have hydrocephalus, are aged 18 to 35 and need treatment in the United States is predicted to exceed 40 000 annually within the next 2 decades. We are developing integrated teams of pediatric and adult medical and surgical specialists to provide continuous, coordinated, comprehensive care for individuals with hydrocephalus in a pediatric setting. This setting will train our future physician workforce on optimal transition care. Coordinated national efforts are also needed.

CONCLUSIONS: Providers need to implement appropriate management and transition care for individuals with hydrocephalus. We must work at local and national levels to transform the care model, improve the quality of health care delivery, and improve outcomes for young adults with hydrocephalus. *Pediatrics* 2009;124:1431–1437

Through medical and surgical advances, the numbers of children with special health care needs are increasing,^{1,2} as are those who survive into adulthood.³ Each year, nearly 500 000 children in the United States with special health care needs become adults⁴ and thus need adult health care services.⁵

Although the exact number of individuals with hydrocephalus is unknown, the condition is not rare and is likely underappreciated.⁶ Annually, individuals with the diagnosis of hydrocephalus generate 69 000 hospital discharges in the United States⁷; approximately half involve children.^{8–11} Each year, US children with hydrocephalus alone generate 38 200 to 39 900 admissions, use 391 000 to 433 000 hospital days, and accumulate hospital charges of \$2.0 billion (2003 dollars).¹¹ In 2003, hydrocephalus accounted for 0.6% of all US pediatric admissions, 1.8% of all pediatric hospital days, and 3.1% of all pediatric hospital charges; in contrast, cystic fibrosis accounted for 0.3%, 0.6%, and 0.9%, respectively.¹¹ Whereas the substantial contribution of cystic fibrosis to pediatric morbidity is widely recognized, that of hydrocephalus is obscure.⁶

Like cystic fibrosis, hydrocephalus is a prototypical chronic condition that follows children into adulthood. In contrast to cystic fibrosis, children who have hydrocephalus and benefited from innovative pediatric treatments often lack adequate care as they become adults. Transition programs for individuals with hydrocephalus are urgently needed.

There are 4 objectives of this article. The first is to review how and why the health care needs of young adults with hydrocephalus are not being met. The second is to present our estimates of the increasing numbers of adults with childhood-onset hydrocephalus. The

third is to describe a novel program that we are developing at Primary Children's Medical Center (PCMC), where integrated teams of pediatric and adult medical and surgical specialists provide continuous, coordinated, comprehensive care for individuals with hydrocephalus and other chronic pediatric conditions. The fourth is to propose educational and national strategies to promote successful transitions for individuals with hydrocephalus.

HEALTH CARE NEEDS OF YOUNG ADULTS WITH HYDROCEPHALUS

To receive comprehensive care, adults with hydrocephalus need continuous access to expert surgical and medical providers. Recognition of surgical complications and access to surgical expertise are critical, because cerebrospinal fluid shunts can continue to fail in adulthood.^{12–14} Medical management for young adults with hydrocephalus must address monitoring for and treatment of adult conditions¹⁵ and facilitation of self-care (eg, medication knowledge, ability to discuss care with providers, insurance knowledge).^{16–20} For young adults with spina bifida, medical management must also address long-term follow-up for associated conditions (eg, epilepsy, cognitive delays, scoliosis, renal impairment, mobility issues)²¹; prevention of secondary conditions (eg, urologic infections, renal calculi, pressure ulcers, osteomyelitis)²²; and facilitation of self-care (eg, bowel and bladder function).^{17–21} Vocational counseling is essential, because employment and financial independence are linked to well-being.^{16,23} Related life issues that the providers need to be cognizant of include autonomy,¹⁸ independent living,^{23,24} social integration,²³ transportation, child care, insurability,^{16,23} psychological and/or behavioral services,²³ assistance for advocate-parent(s),²⁴ and end-of-life issues.¹⁸ Appropriate obstetric management can

result in normal pregnancy and delivery for women with hydrocephalus.^{25–29} Other reproductive issues include genetic evaluation and counseling,²⁸ contraception, parenting, and child care. Finally, patients' holistic well-being, including alternative therapies to address body, mind, and spirit, should be considered. Models of care for adolescents and young adults with hydrocephalus should address each of these health care needs.

Transition Care Models for Young Adults With Chronic Conditions

The goal of transition care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.⁴ It is patient centered, responsive, continuous, comprehensive, and coordinated⁴; however, leaders of the health care system are struggling with this national priority,³⁰ including who should provide transition care, how it should be delivered, and how to finance it.^{31–33}

Several models of transition care for adults with specific pediatric medical conditions exist, including cystic fibrosis,²⁰ congenital heart disease,³⁴ type 1 diabetes,³⁵ and rheumatic disease.^{36–38} We are unaware of any formal transition care models for young adults with hydrocephalus (Harold Rekate, MD, written personal communication, November 7, 2008). Proposed approaches to transition that help to promote self-management for young adults with chronic conditions and bridge the communication gap between pediatric and adult care providers and include appropriate timing and sufficient preparation for the process itself,³⁹ incorporation of a medical home model,^{5,40,41} establishment of

joint clinics between pediatric and adult providers,⁴² and electronic personal health records^{43–45} that include appropriate legal documentation.

Existing transition care models and approaches usually emphasize transition to care that is provided by adult surgical and medicine providers in adult medicine settings. Indeed, only 10% of pediatric neurosurgeons report providing care to their patients as they transition to adulthood (Harold Rekate, MD, personal communication, November 7, 2008). Given a lack of a systematic approach to hydrocephalus transition and adult care, we have termed the state of existing care for young adult with hydrocephalus the “ad hoc” approach.

Ad Hoc Care Model Fails Adults Who Live With Childhood-Onset Hydrocephalus

Ad hoc approaches to follow-up care for young adults most often result in inconsistent and fragmented care. Within 3 years after closing 1 pediatric multidisciplinary clinic, one half to two thirds of patients failed to maintain adequate follow-up.⁴⁶ In the United Kingdom (where health care coverage is universal), two thirds of patients’ shunt function went unassessed after age 16.¹³ Individuals with childhood-onset hydrocephalus and their parents share troubling anecdotes about the ad hoc approach.³³ One 19-year-old woman with shunt failure was admitted to a psychiatric facility for mental status changes, and the mother of a 29-year-old man with recurrent shunt failure was prosecuted for Munchausen’s syndrome by proxy. Inappropriate follow-up results in serious morbidity⁴⁶ and mortality.¹² Adults without a designated provider to coordinate care often fail to maintain adequate follow-up care and subsequently endure severe and potentially preventable morbidity.

Ad Hoc Care Model Exists Because of Economic Challenges

The economic challenge of providing integrated health care for adults with chronic conditions is daunting.⁴⁷ Whereas pediatric care for eligible individuals is supported by state and federal agencies through Medicaid, adult health care for adults with chronic conditions is often fragmented.³³ Obtaining adequate private health insurance is challenging for adults with chronic conditions. Although individuals may qualify for Medicaid, the program has an uncertain future and is complicated by poor provider reimbursement and, therefore, a limited number of participating providers. As a result, health care options for adults with childhood-onset hydrocephalus are few, and although traditional integrated care is essential, it is rarely available.

Ad Hoc Care Models Fail Because Adult Health Care Providers Are not Trained to Care for Young Adults With Hydrocephalus

Health care for these individuals is increasingly delegated to adult surgical and medical practitioners. Historically, adult health care providers have not been or needed to be familiar with pediatric conditions such as hydrocephalus. From a surgical perspective, hydrocephalus that is diagnosed and treated in infancy is a very different disease from the type of hydrocephalus that begins in adulthood as a result of hemorrhage, infection, or tumor.⁴⁸ The pathophysiology of the developing intracranial environment is significantly different from that with which adult neurosurgeons are familiar.

From a medical perspective, adults who live with childhood hydrocephalus have health care needs that are specific to the condition itself, as well as those that are common to all adults. Long-term management of these

young adults’ condition requires specific provider knowledge, skills, and experience with the underlying condition to render ongoing care and prevent unnecessary morbidity and mortality; however, current adult medicine training programs lack a dedicated curriculum that addresses conditions with pediatric onset. The vast majority of adult providers lack the specific knowledge, skills, and experience to provide adequate ongoing care and are ill prepared to manage an adult’s childhood condition, in particular hydrocephalus.⁴⁹ One exception lies in combined internal medicine and pediatric-trained practitioners. The scope and experience of dual-trained providers make them ideal to deliver long-term care for adults with chronic pediatric conditions.

EMERGING CHALLENGE: AN INCREASING NUMBER OF YOUNG ADULTS WITH HYDROCEPHALUS

PCMC is the pediatric center for Intermountain Healthcare (IH), a vertically integrated health care system in the Intermountain West (Utah, Montana, Idaho, Wyoming, and Nevada). We estimate that IH provides 1% of health care in the United States each year, on the basis of the volume of births (32 000; 0.8% of US totals) and pediatric cerebrospinal fluid shunt placements (63; 1.4% of US totals) in 2007.⁵⁰ Although the number of individuals who have hydrocephalus and live in the United States is not known, using IH projections (that incorporate inpatient and outpatient encounters), we estimate that the number of people who live in the United States and are treated for hydrocephalus each year ranges between 120 000 and 150 000. One sixth of IH patients are young adults between 18 and 35 years of age (Flory Nkoy, MD, MS, oral personal communication, June 12, 2008). Using IH projections, we predict the number of young adults who have hydrocephalus, are aged 18

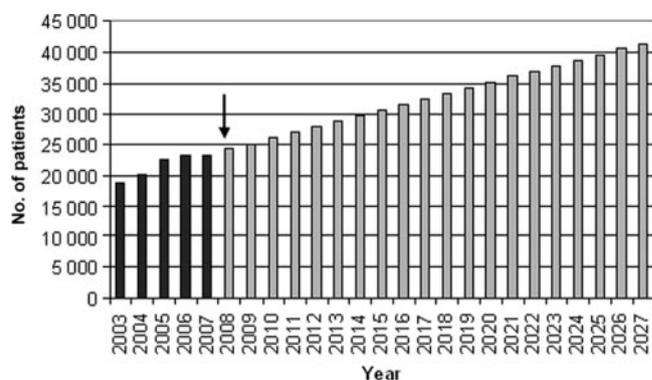


FIGURE 1

Current and projected numbers of patients with hydrocephalus, aged 18 to 35, treated in the United States. Dark bars indicate projections of numbers of patients based on the actual numbers treated at Intermountain Healthcare; lighter bars indicate future projections for young adults with hydrocephalus. Source data from Intermountain Healthcare.

to 35, and are treated annually in the United States will exceed 40 000 within the next 2 decades (Fig 1).

A Novel Care Model for Young Adults With Chronic Pediatric Conditions at PCMC

Whereas existing models and approaches emphasize transition to care that is provided by adult medicine providers in adult medicine settings, at PCMC, we have chosen to maintain continuity of care programs for adults with chronic pediatric conditions such as hydrocephalus. Our goal is to provide an optimal setting where children, adolescents, and young adults with complex medical conditions can receive comprehensive and integrated^{19,20,22,52} medical care and establish continuity of care^{22,52,53} with a designated primary care physician.^{19,20,52} We are developing integrated teams of pediatricians, internists, and medicine-pediatrics-trained physicians to provide care in a familiar setting with nursing staff and social workers. As needed, generalists are supported by medical (eg, neurology, rehabilitation, genetics) and pediatric surgical (eg, urology, neurosurgery, orthopedics) subspecialists. Midlevel providers (eg, physician assistant[s], nurse practitioners) are also employed to provide

continuity.⁵² Outpatient consultations with psychiatrists, occupational and physical therapists, and nutritionists are available as needed. When preferable for both patient and provider, the care team will facilitate transition from the pediatric to adult setting.^{33,43} Transition plans are being tailored to meet each patient's individualized needs and goals.^{33,34,41,53}

Novel Care Model: A Setting for Training Future Providers

We are not aware of any other programs such as PCMC's whereby young adults with hydrocephalus receive ongoing care in a pediatric setting. We believe that this program is necessary in our setting until there are adequate numbers of adult health care providers are trained to treat adults with chronic pediatric conditions comprehensively.^{40,54}

The need for coordinated patient care opportunities and curriculum to improve education in transition care for trainees is certain. Pediatricians are extensively trained to care for children with special health care needs and increasingly must facilitate transition to adult care^{55–58}; however, pediatricians are not trained to care for adults.⁵⁸ In contrast, although well trained to care

for adults, internal medicine and family medicine physicians have little exposure to caring for adults with developmental disabilities.^{58,59} Trainees in pediatrics, internal medicine, family medicine, and surgical specialties must identify the multifaceted needs of adolescents who have chronic medical conditions and will make the transition from pediatric to adult-centered care.

We believe that integrated clinic models that include generalists, nurses and social workers, and subspecialists and subspecialty surgeons as needed are the ideal forum to educate house officers, providing them opportunities to develop their medical knowledge and a framework for successful transition. We are developing curricula to address (1) identification of overall needs of individuals with chronic conditions as they transition from pediatric to adult-centered care; (2) barriers to transition of care; (3) optimal comprehensive medical and surgical care for patients in an adult-centered system; and (4) attitudes, knowledge, and skills required to care for adults with special health care needs.

A NATIONAL EMPHASIS ON TRANSITION CARE IS NEEDED FOR YOUNG ADULTS WITH CHRONIC CONDITIONS

A minimum standard for education in transition care should be developed and used nationally in pediatric and adult medicine training programs, similar to medical genetics for internal medicine training programs.⁶⁰ Current residency requirements established by the Accreditation Council for Graduate Medical Education for trainees in internal medicine and family medicine training programs do not require delivery of curricula to address health care transition. Pediatric and combined medicine-pediatric training programs are required to teach trainees management strategies for chil-

dren with developmental disabilities or special needs within the context of the medical home. Producing a future physician workforce that is competent to render developmentally appropriate health care and health care transition for individuals with hydrocephalus is paramount.⁶¹ Ensuring that these competencies are taught to primary care providers must be an integral component of training and certification requirements.⁶¹ Chronic condition management and/or transition care programs then must undergo evaluation after they are created and delivered to ensure that optimal quality of care for patients with hydrocephalus is provided. We need a future health care system in which all adults, including those with chronic pediatric conditions such as hydrocephalus, receive adult-oriented primary health care from appropriately trained providers.

Novel Care Model: An Economic Solution?

At PCMC, we are providing pediatric neurosurgical and medical care for young adults with hydrocephalus in the pediatric setting. Health care costs are the responsibility of state and federal payment systems. The remaining coverage is provided by a composite of private insurance and charity care. Significant difficulty in our model arises when patients reach adult age. While they are children, private insurers reimburse care because PCMC is the only pediatric specialty center in the Intermountain West. When they become young adults, private insurers can refuse to cover services that could be rendered at one of their contracted adult facilities. Although these facilities may be less optimal, payers are not obligated to continue to cover services at a pediatric specialty center for adult patients. If center certification were available for facilities that specialize in hydrocephalus care, much like that for individuals with cystic fi-

brosis, then access to and payment for appropriate quality care for young adults with hydrocephalus would emerge. Similar specialized programs of coordinated care for children and youth with high medical complexity and fragility have demonstrated cost savings. One such program for 227 children decreased hospital days from 7926 to 3831 and decreased hospital payments by \$10.7 million during a 2- to 3-year study period.⁴² Evidence is building that timely and appropriate medical and surgical care can ultimately reduce costs. With a renewed national emphasis on comparative effectiveness, the care of children with hydrocephalus warrants additional study. For US children who have hydrocephalus and use 400 000 hospital days and \$2 billion in charges (\$2003), there is much room for improvement.

A NATIONAL EMPHASIS ON COORDINATED COMPREHENSIVE CARE FOR YOUNG ADULTS COULD IMPROVE OUTCOMES FOR INDIVIDUALS WITH HYDROCEPHALUS

The Cystic Fibrosis Foundation provides an excellent model of complex, chronic condition management that has transformed quality of care and outcomes for patients of all ages with cystic fibrosis during the 4 decades.²¹ Cystic fibrosis affects fewer people in the United States than hydrocephalus, including 30 000 individuals and 1100 new people each year.²¹ The Cystic Fibrosis Foundation funds and accredits more than 155 care centers nationwide that offer high-quality care, common protocols, and patient support.^{62,63} The high quality of specialized care has dramatically improved outcomes, including lung function and survival for patients with cystic fibrosis.²¹ The Cystic Fibrosis Foundation has achieved these outcomes for individuals with cystic fibrosis by (1) maintaining a patient registry for more than

40 years,²¹ (2) using this registry to define high-quality care,⁶⁴ (3) reviewing and accrediting centers, (4) supporting robust quality improvement initiatives, and (5) providing center-specific reports on patient outcomes.

We suggest that the Hydrocephalus Association play a role in transforming the quality of care for all individuals with hydrocephalus by emphasizing coordinated comprehensive clinical care, following the model of the Cystic Fibrosis Foundation. The authors believe that to achieve what the Cystic Fibrosis Foundation accomplished during the past 40 years for individuals with hydrocephalus in the current health care system, the Hydrocephalus Association would need to partner with a broad range of stakeholders, including patients, families, researchers, care providers, government agencies, and payers to do the following: (1) partner with researchers such as those in the Hydrocephalus Clinical Research Network, a philanthropically funded research network of pediatric neurosurgeons and a partner of the Hydrocephalus Association, to extend a patient registry nationally; (2) simultaneously work with care providers (eg, National Association of Children's Hospitals and Related Institutions, American Academy of Pediatrics, American Academy of Neurologic Surgeons, Congress of Neurologic Surgeons) as well as opinion leaders within the field to define high-quality care; (3) collaborate with researchers and government agencies (eg, National Institutes of Health, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention) to refine and implement quality standards, review and accredit centers, support robust quality improvement initiatives, and provide center-specific reports on patient outcomes; and, last, (4) work with payers (eg, Center for Medicaid and Medicare Ser-

vices) to streamline access to care and care delivery. By emphasizing coordinated comprehensive clinical care, the Hydrocephalus Association and its partners could transform care and ultimately improve outcomes for all individuals with hydrocephalus.

CONCLUSIONS

Medical and surgical care needs for adults with childhood-onset hydrocephalus often go unaddressed. All young adults need continuous and comprehensive care. In particular, those with

chronic pediatric conditions must transition smoothly, regardless of the setting, to adult-centered care. It is paramount that medical and surgical providers become aware of and implement appropriate chronic condition management and transition care. We must work at local and national levels to transform the care model for patients with hydrocephalus.

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